

Cross-Party Group on Cancer

Monday 25th September 2023, 14:00-15:30, Virtual Meeting Via Microsoft Teams

Minute

Present

MSPs

Miles Briggs MSP (Co-Convener, Chair)
Foyso Choudhury MSP
Sue Webber MSP
Finlay Carson MSP

Invited guests

Lorraine Dallas, Roy Castle Lung Cancer Foundation
Theo Burrell, Brain Tumour Advocate
Melanie Mackean, NHS Lothian
Ben Lejac, Young Lives vs Cancer
Rich Hughes, Young Lives vs Cancer

Non-MSP Group Members

Jennifer Cameron, Royal College of Occupational Therapists
Liam Buckley, Less Survivable Cancers Taskforce
Caroline Donoghue, Myeloma UK
Katie Greig, Teenage Cancer Trust
Kirsty Slack, Teenage Cancer Trust
Fiona Brown, Pancreatic Cancer Action Scotland
Christine Boylan, Aberdeen Myeloma Support Group
Leigh Smith, Melanoma Action and Support Scotland (MASScot)
Jen Hardy, Cancer Card
Jo Williamson, Individual member
Christine Campbell, University of Edinburgh
Janis McCulloch, Myeloma UK
Peter Hastie, Macmillan Cancer Support
Jasneet Samrai, Breast Cancer Now
Neil Macdonald, Merck Sharp & Dohme (MSD)
Spencer Green, Lilly UK
Claire Donaghy, Cancer Support Scotland
Graeme Rose, Novartis
Andy McKay, Individual non-member
Madelaine Powell, Individual non-member

George Guy, ICUsteps
Dawn Crosby, Pancreatic Cancer UK
Edwin van Beek, University of Edinburgh
Sharon Cowell-Smith, NHS Lothian
Stella Macpherson, South East Scotland Cancer Network (SCAN)
Josh Hill, Blood Cancer UK
Steve Brown, Roche
Hannah Wright, Jo's Cervical Cancer Trust
Kate Cunningham, Ochre
Janis Munro, Ipsen
Lorna May, Lilly UK
Natasha Johnston, Pancreatic Cancer UK
Lola Adewale, Healthcare Improvement Scotland
Tonks Fawcett, University of Edinburgh
Heather Rankine, Exact Sciences
Liam Mac Lua-Hodgson, The Brain Tumour Charity
George Davidson, GlaxoSmithKline
Helen Webster, British Dietetics Association
Lynsey McPhail, Cruse Scotland Bereavement Support
Eric Shaw, Janssen
Johnstone Shaw, Fight Bladder Cancer UK
Greg Stevenson, Greg Stevenson Consulting Limited
Maria D'Aria, NHS Lothian
Sandra Auld, Healthcare Public Affairs
Ahsan Akram, University of Edinburgh
Noelle O'Rourke, Scottish Cancer Network
Roseanne McDonald, Scottish Cancer Network
Lorna Porteous, Scottish Primary Care Cancer Group
Michael Heggie, Cancer Research UK (Secretariat)
Emily Hindmarch, Cancer Research UK (Secretariat)
Debbie King, Cancer Research UK (Secretariat)

Apologies

Jackie Baillie MSP (Co-Convener)
Norman Pratt, NHS Tayside
Michael Clancy, Law Society of Scotland
Doreen Miller, Cruse Scotland Bereavement Support
Christine Mitchell, Individual member
Martin Coombes, Opened Door Ltd
Jennifer Forsyth, Obesity Action Scotland
Gail Grant, AbbVie
Helen Fleming, Individual member
Douglas Rigg, Scottish Primary Care Cancer Group
Georgina Giebner, British Dietetics Association

1. Welcome & Minutes

Chair, Miles Briggs MSP (MB) opened the meeting and welcomed members. MB briefly described the meeting etiquette and the agenda. Minutes for the CPG on Cancer meeting on 27th June 2023 were then approved without any amendments.

2. Less Survivable Cancers Taskforce Update

MB introduced Lorraine Dallas (LD), Chair of the Less Survivable Cancers Taskforce Scottish Group, to update on the group's work. LD noted that the aim of the update was to provide an insight into the progress made so far and the challenges with regard to less survivable cancers. LD explained that the Less Survivable Cancer Taskforce (LSCT) was set up by a group of 16 charities and organisations whose work is focussed around the less survivable cancers - cancers of the lungs, liver, pancreas, oesophagus, brain, and stomach. Outcomes in terms of both treatment and survival are still very poor for these cancers with only 16% of people diagnosed surviving for 5+ years. Survival rates in Scotland for these cancers have not improved over recent years. In Scotland, this group of cancers represent 9,138 cases annually and result in 7,057 deaths annually. Less survivable cancers form 27% of cancer incidence but 40% of cancer deaths in Scotland. Most of the people diagnosed with these cancers will be diagnosed at a relatively later stage which limits treatment options and impacts on survival. Regarding survival from the less survival cancers, LD noted that Scotland is performing poorly in comparison to other countries. LD stated that we need to improve outcomes and survival by earlier diagnosis, faster diagnosis, optimising pathways, better supportive care, and boosting investment in research.

LD then introduced Theo Burrell (TB) to share her personal experience of cancer. TB explained that in June 2022 she was diagnosed with a glioblastoma which is a grade four incurable brain cancer. It is the most common high grade primary brain tumour in adults and the life expectancy after diagnosis is 12-18 months. TB noted that brain tumours are the biggest cancer killer for people under 40 which includes children, but it receives less than 2% of cancer research funding which has resulted in slow progress, particularly with regards to treatment. TB provided a first-hand account of her own diagnosis, treatment, and the devastating impact of this. Theo highlighted statistics which showed that 41.6% of brain tumour patients presented at A&E compared to 17.9% who were referred by their GP. To highlight the impact of delayed diagnosis, TB then told the group about some of her friends who were initially misdiagnosed before being diagnosed with brain tumours. Theo noted the lack of money spent on brain tumour research and that treatment options have not changed over the past forty years. TB finished by highlighting the importance of GPs getting better at spotting the signs of a brain tumour, with symptoms not going unignored.

Melanie Mackean (MM), a lung cancer consultant oncologist from NHS Lothian, then provided a clinical perspective. MM noted the improvements in lung cancer treatment, including seventeen SMC approvals for new drugs, and highlighted the importance of starting treatment early. She highlighted some of the progress that has

been made in Scotland, including the optimal lung cancer pathway and national tumour management guidelines. MM stressed the need to implement lung cancer screening in Scotland and that we have fallen behind NHS England. She welcomed the Scottish Government setting up the Scottish Expert Advisory Group, which will assess the challenges and opportunities of lung screening. One of the biggest barriers is the patient population and reaching those who would benefit most from lung screening. MM reiterated that lung cancer needs to be implemented at pace and needs to be done sensibly and clinically securely. She acknowledged the governance around screening needs a huge amount of work. Melanie noted she was pleased that the optimal lung cancer pathway features in the Scottish Government's new Cancer Strategy but that there are big barriers to implementation in terms of radiology and PET scanners. Regarding PET scanners, Scotland is under-resourced compared to NHS England and other countries. Although there are areas that need action MM can see change and hopes that we can move forward so that patients can benefit. Melanie finished by highlighting work at St John's Hospital on keeping lung cancer patients fit whilst they wait for treatment.

MB thanked all the speakers, particularly TB for sharing her story, and opened to questions from attendees. Finlay Carson (FC) asked if there is a direct link between public awareness campaigns and the stage of diagnosis of less survivable cancer. FC also noted his concern at GPs not referring patients sooner when they are displaying signs and symptoms of cancer. LD noted that people are often not aware of the signs and symptoms and don't necessarily realise the significance, so we need that education for the public. LD highlighted the good work done by the detect cancer early team in this area. She added that we also make the most of our stretched primary care diagnostic resources to ensure that where necessary people presenting with symptoms are escalated. TB said she found it a battle getting anybody to listen to her and she thinks one of those factors was because she was young. TB said a possible solution is making GPs better understand that brain cancer is indiscriminate and not linked to age. MM echoed TB's comments regarding age and said that there is work to be done in this area. MM noted that non-smoking lung cancer patients who tend to be younger often struggle to get referred for diagnosis which leads to a poorer prognosis.

George Guy (GG) said that he was an 11-year survivor of oesophageal cancer and spoke about his own diagnosis. GG queried whether GPs should have a list of indicators of harder to detect cancers to help refer people earlier. MB noted that GPs might only see one of these cancers in their whole career, so it's very difficult for them to diagnose. He asked how that's changing and whether the new Cancer Strategy is going to improve that. LD noted that we have referral guidelines and suggested the new rapid cancer diagnostic services should help. MM praised the work of GPs and said that there are some rare diseases that have red flags. MM suggested that there is perhaps work to be done at a very early stage in medical careers in identifying the red flags for these cancers. Dawn Crosby (DC) noted the lack of investment in research of these cancers and the need for investment in tools for GPs to improve detection. DC also said that the rapid cancer diagnostic services are a huge opportunity for Scotland to pick up these cancers earlier. She noted that the Scottish Government is looking at rolling these services out by 2026. DC questioned why it should take so long and said that every health board should have

one as soon as possible. DC also highlighted the upcoming cancer referral guidelines review.

MB thanked Lorraine, Theo, and Melanie for their presentations and for an interesting discussion. MB suggested the CPG return to this issue going forward.

3. Running on Empty: Cancer Costs for Children, Young People and Families in Scotland

MB welcomed Ben Lejac (BL) and Rich Hughes (RH) from Young Lives vs Cancer to present on the findings of their [Running on Empty](#) research report. BL explained that the Running on Empty campaign and research is focused on the costs of travelling to cancer treatment faced by young people and families. In Scotland, Young Lives vs Cancer support children and young people (aged 0-25) who are diagnosed with cancer and their families by providing social workers, financial support, accommodation, and by amplifying their voice.

RH stated that the research consisted of an online survey and follow-up interviews, with a total of 259 people taking part. Participants consisted of young people (aged 18 to 26) and parents or caregivers of children and young people, aged under 27, from across the UK. RH added the evidence shared in the presentation is based on the findings and discussion with young cancer patients in Scotland. RH noted that each year, around 300 children and young people in Scotland are diagnosed with cancer. To receive the specialist treatment they need, they and their families often have to travel long distances, several times a week, and sometimes this will last for years. This is an average of about 40 miles away from their home to their main principal treatment centre. Rich added that cancer patients and their families have very little choice in the treatment centres that they go to. The report found that young cancer patients and their families are travelling around 400 miles a month and spending 9 hours a month travelling to and from treatment. One in five young cancer patients in Scotland need to travel to another country for treatment (mainly England).

Not only can this be physically and emotionally exhausting, but it can also come at a significant financial cost. RH noted the report found that travel to and from treatment each month costs an average of £250. Those travelling more often, further, and for longer, on average spend more getting to and from cancer treatment. The research found that the most common and significant of all the extra outgoing costs was the cost of travelling to and from treatment. RH added that for many, frequently having to travel to and from cancer treatment can also result in lost household income and earnings, through taking additional holidays, sick and compassionate leave, changing working hours and patterns, and in a third of cases stopping work completely. The report found that four in five families experienced a decrease in income. The evidence suggests that the longer the treatment lasts, the further they have to travel, the more likely they are to experience this loss in income and earnings. For those households experiencing a loss in income, this averages at more than £6,000 a year. For one in five households this loss exceeds £10,000 a year.

RH noted that current support is inadequate in covering the travel costs for many young cancer patients and their families. RH said that despite there being a range of

different support mechanisms in place, particularly in Scotland with the Young Patients Family Fund, many young cancer patients and their families are still being left to pick up significant costs. The most common barrier around access and support was not being aware the schemes existed. Young cancer patients and their families reported that communication about support was ad hoc. Young cancer patients and their families appeared to learn from each other rather than through formal channels or structures. Another barrier was eligibility, which included both the age of young cancer patients and the type of visits they were making. The research found that the young cancer patients were more likely to receive support from charities with the cost of travel than they were from government schemes. RH noted that about half of young cancer patients and their families in Scotland received some form of charity support, which helped with their travel costs. However, in most cases these tended to be one off grants. As a result of all this, only one in five received financial support that covered the cost of their travel.

RH said that this means many young cancer patients and their families are struggling to pay for the costs of travelling to and from cancer treatment. The research found that two in five young cancer patients and their families struggled to afford travel costs. For most, these financial struggles commonly resulted in them having to make a range of sacrifices. These often included going without much needed social and recreational activities, cutting back or going into their savings, and taking on debts. Less commonly, this also resulted in families having to cut back on food, falling behind on household bills, selling their possessions and assets, and fundraising to help meet costs. RH noted that at a time when young cancer patients and their family should be focusing entirely on getting through treatment, they're often dealing with the worries that come with the financial impact. RH stated that this can all have a significant negative impact on young cancer patients and their families' financial security, health and wellbeing, and future prosperity, leaving them running on empty.

BL explained that on the back of the report Young Lives vs Cancer are calling for governments across the country to provide a Young Cancer Patient Travel Fund, however the situation is slightly different in Scotland as we already have a Young Patients Family Fund. This is the only resource of its kind anywhere in the UK and was launched by the Scottish Government two years ago and does provide some support for travel costs. The Young Patients Family Fund (YPPF) provides vital support for families of under-18s in inpatient care. However, the research showed that only one in five respondents in Scotland said that they had access to support, so it's not meeting everyone's needs. Ben noted that lots of young people and families who would benefit from YPPF support cannot access it under current eligibility. These three groups are 18–25-year-olds, outpatients, and day patients, and those travelling outwith Scotland. BL explained that Young Lives vs Cancer are calling for an expansion of the TPF to cover these three groups. They are also calling for a review of the Fund and increased awareness-raising efforts, which would benefit families and young people.

MB thanked Ben and Rich and initiated the Q&A by asking if the charity's research looked at what point people did ask for help and how that can be changed. MB also asked if some health boards still have patient transport networks available and whether there is data available based on people's experience with this service. RH said that they didn't ask specifically on when they accessed support, but anecdotally

many people didn't know at an early stage that there was potentially some funding available. RH noted that there were mixed reasons for this, but awareness was a big issue. On patient transport, RH said largely people wanted to travel by car to treatment because of convenience, difficulties accessing patient transport, difficulties regarding timings, and young cancer patients being immunocompromised. However, they do have some data on patient travel services.

FC said he was very aware of some of the issues raised in the presentation as he represents a rural constituency. FC noted that cancer patients in Dumfries and Galloway travel to Edinburgh for treatment despite it being closer to Glasgow. He asked if there needs to be more information on the options available to patients and whether there should be an obligation on health boards to do this early in the treatment pathway. BL said that sometimes the options available are quite narrow for children and young people. That's particularly the case for those who have to travel outside of Scotland because they need access to a particular form of treatment that isn't available in Glasgow or Edinburgh. BL added that more information, which is accessible and available at an earlier stage, would be welcome.

4. AOB

MB noted that this year's Scottish Cancer Conference will take place at the University of Strathclyde's Technology & Innovation Centre in Glasgow on Monday 27th November. The theme of the conference will be: "Scotland's new Cancer Strategy – Ten years in the future, what does success look like?".

He added that this year's conference will examine what the strategy promises to deliver over the next 10 years. The event will examine why it is so important, what needs to happen to ensure it is implemented and how we will know that it has been a success. MB noted that registration for the event will open shortly.

MB also noted that September is Blood Cancer Awareness Month.

5. Close of Meeting

MB noted the next meeting date is still to be confirmed but will take place in December and will be the group's AGM. The secretariat will be in touch with more details on the next meeting agenda and how to register.